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Participation of patients in decisions about treatment for cancer

Desire for information is not the same as a desire to participate in decision making

The primary aim of treatment for cancer is to improve the quality of life of patients by curing them or producing a long and worthwhile remission and ameliorating their worst symptoms. For many types of cancers, however, the most appropriate management is not always clear or based on the best evidence from well conducted randomised controlled trials.

Clinicians may have more than one therapeutic option to offer patients and there are many calls for more involvement of patients in decision making about their treatment. Two fundamental issues should be determined when discussing treatment choices with patients—their own preferences about the amount and type of information that is needed and their actual rather than perceived desire for participation in decision making. A clear distinction needs to be made between a desire for information and a wish to assume responsibility for decision making. They are not one and the same thing. In one study of women with breast cancer, improvements in quality of life brought about by reduced anxiety and depression and better adjustment were primarily related to satisfaction with information they got, not merely involvement with decision making about the type of surgery.¹

Many studies have shown that patients want much more information than their doctors believe they do.² We also know that the ability of doctors to predict which patients want an active, shared, or passive role in decision making is very poor in palliative care and when active, potentially curative treatment is discussed.^{3,4} Patients' preferences about choice of treatment are poorly understood and usually based on intuitive assumptions about their perceived intelligence, age, or quality of life. This problem is not confined to the United Kingdom, although the poor ratio of oncologists to patients does mean that good patient centred communication about choices available and their consequences is easily omitted in busy clinics. We await with interest more results from the study to understand prognoses and preferences for outcomes and risks of treatments from the United States.⁵

The choices of treatment put before patients should involve an adequate and objective appraisal of information, delivered in a patient centred manner backed by information booklets, audio and video tapes, and references to good websites such as those provided by CancerBACUP, the new National electronic Library for Health (NeLH), and the DIPEX database.⁶⁻⁸ Unfortunately even when evidence concerning improved survival or disease free intervals exists, data on quality of life are either missing, sketchy, or not well integrated into the analysis of overall benefit. There is some evidence that doctors do not collect accurate information about symptoms that affect quality of life; consequently patients may be agreeing to different treatments without being aware of their side effects.⁹

Further, doctors admit to having difficulty integrating the results from formal assessment of quality of life by questionnaires into clinical management, preferring to rely on their own clinical impressions about tolerability or impact of side effects.¹⁰ Arguably in some situations, including adjuvant therapy and palliation, these quality of life parameters might be the most important areas of information that a patient requires about likely benefit before consenting to treatment.

Patients cannot participate in decision making to their desired extent unless they have the right types of information, given in ways optimal for their own level of understanding. There is a compelling need for training and other interventions to help communication between doctors and patients about the likely and preferred therapeutic goals and priorities of treatment. True patient participation, which may include an expressed preference by the patient to assume a more passive role about the type of information they require, and involvement in decision making is, for most, an unachievable goal unless we see some real improvements in the current system of healthcare delivery. Too many patients are being seen by too few doctors in over burdened clinics with inadequate support staff for meeting adequately the individual information needs of patients with cancer.

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